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# It's All of the Above: Benefits of Working for Individuals with Spinal Cord Injury

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**Background:** The majority of research on employment among persons with spinal cord injury (SCI) focuses on the employment rate at a given point in time to the exclusion of quality employment outcomes. **Objective:** To identify the employment outcomes of greatest importance as defined by those with SCI who have worked since injury. **Methods:** A qualitative approach was used with 6 focus groups at 2 sites (Minnesota and Georgia). Participants ( $N = 44$ ) were a minimum of 10 years after injury and had been employed at some point after SCI. We identified participants through a 40-year longitudinal study of SCI and a community resource. A combination of homogeneous (race/ethnic minority group, female group) and heterogeneous groups were convened. A semi-structured interview format queried participants about personal, environmental, and policy-related factors that impacted obtaining, maintaining, and advancing in employment. **Results:** Seven overlapping themes were identified under the 2 broad categories of compensation and subjective well-being: (1) salary and what it can support, (2) health insurance and other fringe benefits, (3) promotions and recognition, (4) social connection and support, (5) job satisfaction and enjoyment from working, (6) making a difference and helping others, and (7) psychological and emotional health. **Conclusion:** The results indicate several common themes among persons with SCI who have successful employment histories, suggesting that the benefits of employment are multifaceted and go beyond monetary compensation. **Key words:** employment, qualitative, spinal cord injuries

Spinal cord injury (SCI) can present barriers to obtaining and maintaining employment, as indicated by unemployment rates that can exceed 80% for persons with more severe injuries.<sup>1</sup> Nevertheless, people with SCI can and do work – even those who have the most severe physical impairments. Moreover, research repeatedly shows a positive relationship between employment status and quality of life after SCI.<sup>2-4</sup>

From a societal perspective, full-time competitive employment is the goal. Individuals who work add to the tax base and take fewer resources from the system. As such, the primary focus of vocational rehabilitation is to assist persons with disabilities to gain employment. Concerns about losing economic and health benefits is a common reason why people choose not to return to work after SCI.<sup>5</sup> This fear of losing benefits is often tied to a

reluctance to separate from Supplemental Security Income and Social Security Disability Insurance and the safety net these programs provide.

Although obtaining work is an important employment outcome, other quality indicators of employment must be considered.<sup>6</sup> If we are to improve employment outcomes, we must better understand the wide range of outcomes that include not only *work participation* (hours spent working, job retention, and job tenure) but also *work quality indicators* related to types of jobs, opportunities for promotions, job satisfaction, and earnings and benefits throughout the work life cycle.

Our objective is to identify the employment outcomes of greatest importance as defined by persons with SCI who have worked since injury. A qualitative approach was used to allow for

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new insights into the processes<sup>7</sup> and to provide researchers, program developers, and policy makers with a myriad of potential factors that may impact work life.

## Methods

### Participants

Institutional review board approval was received prior to study initiation. The majority of participants were identified through an ongoing longitudinal study of SCI in which participants were initially enrolled through rehabilitation hospitals in 2 states, Minnesota and Georgia. All participants were a minimum of 10 years after injury at the time of the qualitative study, ensuring they had at least a decade of living with SCI from which to draw employment experiences. Additional participants were identified from a community resource in Minnesota.

Only individuals who worked at some point after injury were eligible to participate. We used stratified sampling to recruit a balance of participants based on multiple characteristics including current employment status, gender, race, and education (high school vs some college or more). Groups were delineated based on specific characteristics, such as education, gender, or race. Individuals with a high school degree or less were invited to participate in the blue collar group, whereas individuals with college experience were asked to be part of a white collar group. In Georgia, there were sufficient potential participants of racial and ethnic minority backgrounds to conduct a group consisting solely of individuals from minority backgrounds; however, this was not an option in Minnesota. Rather, in that area, females with SCI were a distinct minority; therefore, a women's group was scheduled. These groups were organized to allow unique issues and experiences of these traditionally underserved populations to be articulated. Persons who fit into more than 1 category chose the group that best fit their schedule. A total of 6 focus groups were conducted at 2 sites (Minnesota or Georgia) consisting of between 4 to 9 participants each for a total of 44 participants. **Table 1** summarizes participant characteristics.

**Table 1.** Participant characteristics

Characteristic	% or mean (SD)
Gender	
Male	70
Female	30
Race/ethnicity	
Non-Hispanic White	83
Minority	23
Current age, years (range, 30-73)	52.2 (10.05)
Age at injury, years (range, <1-47)	21.57 (9.76)
Time since injury, years (range, 14-58)	30.66 (2.83)
Current work status	
Working	50
Not working	23
Retired	27
Level of injury	
Cervical 1-4	11
Cervical 5-8	37
Thoracic	45
Lumbar	7

### Data collection procedures

Informed consent was obtained prior to the start of the focus groups. Groups were conducted at the 2 sites and were audio and video recorded. Groups followed a semi-structured format lasting between 2 and 3 hours. Two facilitators led each group – one led the discussion and a second took notes. The core of the questions was designed to elicit information about the personal, environmental, and policy-related factors influencing job attainment, maintenance, and advancement following SCI. In particular, participants were queried about what constituted quality employment outcomes. The primary question associated with this area was, “Over the years, what employment outcomes have meant the most to you?”

Recordings were professionally transcribed and returned to group facilitators for review. Errors were noted and corrected. Once “cleaned,” transcripts were uploaded into NVivo10 (QSR International, Burlington, MA) qualitative software. Transcripts were reviewed multiple times before being coded by 2 authors to extract topics, themes, and patterns from the source documents. In addition, transcripts were coded into various nodes based

**Table 2.** Themes by group type

Themes	White collar	Blue collar	Women's	Minority
Quality outcomes	23	32	10	17
Earnings & income	6	9	3	1
Fringe benefits	7	3	0	1
Promotions & recognition	7	10	1	2
Social connection & support	6	9	0	9
Job satisfaction & enjoyment	4	15	5	4
Helping others & making a difference	3	15	6	3
Emotional & psychological health	11	5	1	3

on participant, region, and group type. Given the volume of narrative, what follows is a distillation of perspectives highlighting one of the issues that emerged – quality of employment outcomes.

## Results

Narratives fell into 7 overlapping themes that were grouped under the 2 broad categories of compensation and subjective well-being. Specific themes were (1) salary and what it can support, (2) health insurance and other fringe benefits, (3) promotions and recognition, (4) social connection and support, (5) job satisfaction and enjoyment from working, (6) making a difference and helping others, and (7) psychological and emotional health. Different groups appeared to focus on different types of themes, with individuals in the women's group and blue collar groups talking most frequently about the satisfaction they derive from helping others and those in the white collar group talking most frequently about fringe benefits and the importance of work for emotional and psychological health (**Table 2**).

### Category: Compensation

#### *Theme: Salary and what it can support*

Getting paid for what one does was discussed as a primary and important benefit of employment. In some cases, participants identified salary and money as the most valued outcomes. For example, as heard in the blue collar group in Georgia:

*Facilitator:* What part of the parts of employment are most important to you?

*Ronnie:* Paycheck.

*Facilitator:* The size of the pay check?

*Ronnie:* The size of it and, really, that's it, the size matters.

Another respondent said, "For me, it's just money. The money drives me."

For others, the benefit of working was not as directly linked to the money itself but rather to the things one could do or purchase with a salary and the lifestyle it could provide. As noted by Max in the white collar group in Georgia, "I think everyone would agree that going to work, financial benefits are self-evident. You've got bills, food, kids to send to school."

The narrative below reflects another example of how salary from employment allowed participants in a focus group in Minneosta to obtain the things they valued in life:

*Ellis:* When you work, you get the other things. ... Well, I like to fish. I liked cars, so I bought cars. I worked on cars. The work and the reward. I've been married 34 years.

*Chester:* I would visualize things like gee, it would be nice to have a room to myself instead of a roommate. Then I got that. Then it would be nice to have an apartment. Then I got that. Gee, it would be nice to have a house. Then I got that. Gee, it would be nice to be married. I got that. You had to visualize it.

Those responsibilities often keep people working, just as they do in the general population. As noted by a participant in the Georgia blue collar group, "Oh yeah. I own my house. I have to pay my bills. So that, and I also have two kids

(twins).” For another participant in a Georgia group, maintaining employment allowed him to save enough to send his children to college.

*Karl:* The main reason that kept me there was to make sure I could pay for my kids’ education. I made up my mind that they didn’t have to go through what I went through. So I’ve got one that’s a financial analyst and one that’s a doctor, so I’m happy. It cost me like hell, but I’m happy.

Despite the emphasis put on salary, though, most participants appeared to feel that salary was important but not everything. As noted by Pam, “Getting paid is great, but I’d rather be fulfilled by what I do.” Jeannette in the same group noted, “I’m constantly [complaining] I’m not making enough money, and I’m always pushing. But I’ve been maxed out for year as far as my salary level goes. It’s that sense of purpose.”

One particular nuance is reflected in the statement by Ellis, a retired white male with paraplegia: “It certainly wasn’t the money. We all knew we weren’t going to get rich. We ended up okay.” This statement may reflect that a portion of the participants decided to remain on social security and Medicaid while also working. For these individuals, the amount they could make was limited by the access to state and federal disability benefits.

### ***Fringe benefits***

Health insurance and fringe benefits were discussed as a quality employment outcome. Ronnie, a white male with tetraplegia, stated, “Benefits are important; we usually take lower pay for benefits.” Eloise, an African American female with paraplegia, tied benefits with thinking beyond yourself or that moment: “You got to think for the future, your 401Ks, all your benefits, insurance. The insurance counts a lot.” In contrast, compensation or public assistance programs may provide income, but they do not allow a person to save for the future – a fact that was pointed out by participants in Minnesota (who also discussed ways they had used to get around this).

Level of fringe benefits, then, influenced participants’ decisions to take a job or remain with a job or company. As noted by several participants: “One of the reasons I went there was because of their outstanding health benefits.” For Bill, a

retired male with high level tetraplegia, the long-term care insurance offered through his employer really made a difference:

Working where I was, I was afforded the opportunity to purchase long-term care insurance. I didn’t know if I’d be eligible, but I thought I would; so I took it out, paid on it from ’93 until ’06. That’s allowed me to remain living my own home with 24/7 care. I have a pretty good quality of life.

### **Overlapping categories of compensation and subjective well-being**

#### ***Theme: Promotions and recognition***

The importance of promotions and recognition in providing a sense of being valued at work was also evident. Several participants noted an inability or unwillingness to take on jobs with different requirements, but all appeared to appreciate being offered the opportunity:

But like I said, I enjoyed doing what I was doing. I got promoted, and I got to the point where I told them I didn’t want it because I didn’t want to relocate. So pretty much I was locked into my job. I don’t mind traveling but home is where I’m going to be. I was satisfied.

This statement also appears to reflect how the degree of satisfaction with promotion may be limited by other factors. Similar to salary, promotions and recognition provide positive feedback about the quality of work that can enhance self-esteem. As noted by Peggy in the white collar Georgia group, “Recognition has been important to me because it’s helped me feel self-accomplished and knowing that I’m on track of accomplishing more things and giving me the strength to keep going, striving for more.”

Another woman with paraplegia in the white collar Georgia group [Victoria] talked about her experience with employment following SCI – from being hired to moving up to leadership roles including managing several dozen people and a multimillion dollar budget. The pride with which she described her position and the responsibility it entails was evident in the way she discussed how her career developed.

One or 2 participants articulated that it was not just the appreciation they were motivated by, but the adoration. The following was a quote from a

Larry, in the blue collar group in Minnesota, who was doing motivational speaking and disability education for pay at schools and colleges:

You mentioned during break you appreciate my input. Well you ought to see what a thousand people do after a 90-minute presentation when a principal says there's no way he can keep somebody for 90 minutes. The only reason people leave is for lunch, and 50 people come around, and they don't want to leave. On my website I've got pictures of kids. There was a guy on a 12-foot stepladder looking down at these kids, and I'm playing with one kid and all of them are swarming around me. How can you not get jacked by that?

### Category: Subjective well-being

**Theme: *It's always been about a sense of purpose.***

This theme is labeled based on a quote from one of the female participants in Minnesota [Pam]. For many, having a sense of purpose was both a motivation for and an outcome of working. Working allowed them to make a difference in the lives of others and society as a whole.

The following narrative is from Larry, the individual with tetraplegia from Minnesota who worked as a motivational speaker. His statements reflect the importance given to helping others.

*Larry:* You make a connection. People come up to me and say they never thought about this. I had a girl write me a letter that told me she tried to kill herself seven times; and because of my program, she'd never do it again. And I've had dozens of things like that.

*Nicolas:* Ditto.

*Larry:* I literally stopped people from killing themselves.

*Facilitator:* So the benefits of helping others.

*Larry:* Yeah, that's why I got hurt. I know why I got hurt. I couldn't always say that. It took me a while to get to that point, but at that point now. I'm far enough down my journey that I can look back and say, "That's why this happened, and this is why that happened." Do I like it? No! I wish my accident had never happened, but I meet a lot of people.

### Others repeated this theme:

*Pam:* For me, it's always been about a sense of purpose. Getting paid is great, but I'd rather be fulfilled by what I do, which is why I went to law school and did the hands-on, little-guy things I like to do. That has never changed. That's the most important thing in work.

*Jeannette:* Personal happiness is important, but I've got to know I've made a difference, I've had an impact, I've made somebody's life better, I've solved a problem. I've made a difference, and that's important to me.

*Dora:* I'll say the same thing. Teaching, you see it with the kids; how you touch their lives.

For others, their jobs allow them to help others in smaller but still meaningful ways, and that also appears to provide a sense of importance to them.

*Frank:* Now it's really different. I don't interact with my co-workers on a personal level, which is fine, just different... So I get more job satisfaction from feeling like I make a difference helping someone get scheduled. That's what I leave with, the satisfaction: I maybe can help this family out a little by doing this or that.

Still others focused on the value of their job to society as a whole, as opposed to individuals; however, this variation was not very prevalent.

*Yukami:* Making a contribution to society is huge. By working, we contribute all of that in our way. ...We all have a place, and being able to find our place. We all want to be helpful, needed, feel useful. Through our job, it provides some of that.

Helping others with disabilities appeared to be especially rewarding to some.

*Katrina:* My husband also has a disability, and we are dedicated to making sure younger and newly injured people have the same opportunities we had. We had to fight for a lot of those opportunities to make it happen; but when I look at the young people going through, so many of our kids are getting full college scholarships.... They're getting full scholarships to major universities on their academics and athletic abilities. Our kids travel all over the world. They're making something out of their lives. That's what's important. [Applause]

For others, educating others about disability issues gave a sense of satisfaction and pride. This could be done directly through presentations or indirectly by providing a role model of an individual with SCI who was employed – letting others know what is possible.

*Allen:* ...So employment and volunteer work that I do and then my regular out and about, it is a social thing. It's also educational for me because I like to meet other people with disabilities, just random conversation. Their mindsets are so, because of support groups or lack of support, a lot of them feel "I'll get my little piece of change, stay home." Or when I tell them I'm a homeowner now. Even before I was a homeowner, I got my own place or whatever, they're like, "Wow, you really live like that?" So it is a social thing; it's also an

educational thing. It's almost like I'm mentoring but not on purpose. Again, I talk a lot [laughter].

### ***Theme: Social connection and support***

The social connection and support experienced at work was also important, as indicated by Yukami, "Support system makes all the difference." Co-workers share responsibility and work load. Frank, a man in the blue collar group in Minnesota noted, "So I had co-workers, so it was easier to take time off or switch shifts. That was a blessing."

Work also serves as a place to socialize and make friends, providing interaction that may be limited due to injury. Benjamin, a white male with tetraplegia, talked about making friends at work, "I always like to make new friends. That's what I got out of work. I made new friends." Kevin, a white male in the Minnesota white collar group, reinforced that statement, "Social interaction is extremely important. For me it's everything. I love my co-workers, the people I met. Some of my customers are my friends I've had for years."

The quality of the relationships established at work influenced the desire to work. For example, Vernon, an African American male with low-level tetraplegia, discussed the importance of good morale, "Good morale. Morale is like people around you having a good attitude. Sometimes people come around with a bad attitude. So good morale." Having fun at work was an aspect of quality relationships raised by Karl, an African American male with high-level tetraplegia:

I had a CEO tell us if you come to work and it's not fun, you need to find you another job. He believed in you got to have fun on the job and relate to the people around you, make jokes. If you don't make it fun, work can be hell. But if you have fun and the people around you are happy, it makes your job a whole lot easier.

The importance of this is articulated by Brent, a male participant with both SCI and traumatic brain injury (TBI) in the blue collar group in Georgia. He pointed out, "See, injury, sometimes takes away your social life. It totally takes it away because you have to adjust what you used to do." Employment may provide an opportunity to experience social connections with others.

Louis, an African American male with tetraplegia described his experience with telecommuting for

work, which may be a viable, worthwhile option for some persons with SCI:

It's still social because you get to interact with everybody else on the job. That was what I was kind of worried about if I needed help. But when I started there like "We all talk while we're on the job." So I was meeting new people, and I was meeting people from all over the country. Now with the Internet, you can face chat with somebody while you're interacting with a customer; so if I needed help, I can face chat with someone on the job. So you still meet people and interact. The way everything now is changing, it's actually easier to meet and interact to get help quicker than if I was physically there.

Finally, for some participants, working provided a sense of community outside of the workplace as well. Edmund, an African American male with tetraplegia, explained:

But only with that, I work at night from 11 o'clock to 7 in the morning. Actually, I got to go tonight. So with me riding the public transportation and out there at night with the elements (rain, snow, or all that), I got bus drivers that I don't even know. They know I ride the route. They look out for me. Like the driver said last night, "Where have you been? I ain't seen you in a week."

### ***Theme: Job satisfaction/enjoyment from working***

Job satisfaction and enjoyment from working were motivating factors for seeking and maintaining employment. A key feature of job satisfaction was finding what you do interesting and having the opportunity to learn or try new things. For example, when asked what the important parts of working are besides salary, Charlie, a white male with paraplegia in his 40s replied, "What you're doing. Whether you enjoy the job and it's interesting." Yukami indicated that "learning new skills" was one way to find enjoyment through work.

Having fun at work is another aspect of job satisfaction. Kevin, a retired white male with paraplegia from Minnesota stated, "I love the people you meet and the experiences. They call it work, but it doesn't have to be work if you have a lot of fun too." Conversely, if the enjoyment from working goes away, the likelihood of leaving that position increases. A white female participant with paraplegia from Minnesota [Katrina] detailed, "I was so burned out with the [stuff] my boss was giving me that I thought it was a perfect time to

leave.” Furthermore, salary and earnings do not compensate for lack of job satisfaction. As Lisa, a female participant from Georgia stated, “I’m not going to take a job even if it’s a big paycheck doing something I’m going to be miserable doing.”

### **Theme: Psychological – emotional health**

Previous research has discussed the impact of SCI on psychological and emotional health.<sup>8-11</sup> In this study, participants identified a positive effect on psychological and emotional health as a quality outcome of employment. An idea noted by many participants was that work kept them busy, helping them avoid depression, addiction, and morbid thinking. Among the statements supporting this was one from Roy, a male in the white collar group in Minnesota:

I think that’s a big thing, just getting back to work helps out a lot because you don’t have time to be depressed. Or I don’t. I stay so busy, when I get done with work, I just want to come home and watch TV and go to bed to get ready to do it again the next day. You don’t have time.

When discussing the possible impact of not working, Richard, a white male from Minnesota stated, “That’s when depression and all those things start kicking in, and the beer bottle gets a little closer.” Another participant expressed, “You got bored. A lot of people aren’t with us any longer because they lost their reason to live.”

Another aspect of psychological and emotional health identified was the independence and productivity experienced through working. As Susan, an African American female in the Georgia group, indicated:

Getting out and being independent again. Not feeling like you’re sitting there having someone waiting on you. Just what you were doing when you were walking. It’s really about being independent again. I want to make my own way.

Another white female, Peggy, stated, “It definitely makes you feel like a more productive person. That’s always been important for me and what I consider to be important to be a part of the world.”

Along with independence and productivity, participants felt work aided them in finding their

identity and increased their self-worth. Stated by Yukami:

I think it’s finding your true identity beyond the identity that was given to you because of the disability. For me, it’s been very important. Work has helped me define myself beyond being a mother, wife. Not that it’s not great, but beyond that.

Issues of identity were also evident when participants talked with pride about their work ethic and never considered the possibility of not working.

*Chester:* But 15 years ago, you’re in the middle of your work life, what kept you going?

*Kevin:* I never, like for all of us, it isn’t always rosy, and it’s perseverance. It’s the marathon deal. Never thought about quitting.

*Chester:* The way to go.

In addition, when asked what the most important parts of working were, multiple voices chimed in that self-worth was essential.

For most participants, working was almost therapeutic. Larry stated:

One thing is that even if my job ended tomorrow, the important thing of continuing on in some capacity is important to maintaining health and mental focus and lifestyle whether it be working in my garage, a job at Home Depot.

A quote from him sums it up, “I love doing what I do! It’s my passion. It’s like therapy for me.”

### **Combination Statements**

For many participants, the quality indicators associated with employment were not singular but were multiple and complex. As stated by Bill in Georgia, “Can we just say refer to Maslow’s Hierarchies of Needs?” This was further articulated by the other participants in the group:

*Victoria:* Salary, attainment, the sense of helping people because that’s a field a lot of us are in (being able to change people’s lives), ability to be promoted (a career ladder not stuck in one place), opportunities based on your skills and not it felt good to give you an opportunity. And equal opportunity that I’ve had. It was whatever I wanted to make of it, and it was my choice. Everything, besides some luck being at the right place at the right time, equal opportunity to succeed.

## Discussion

Results from this qualitative study highlight the importance of employment as a means of financially supporting one's self and family, accessing health insurance and other fringe benefits, promoting relationships and social networks, providing a sense of purpose and accomplishment, and supporting psychological and emotional health. Participants felt better about themselves when they had a reason to get up in the morning, a place to go, and activities to accomplish that they view as important and valued by others.

Findings from this study also appear consistent with existing research on employment. In the general population, earnings from employment have been found to be strongly associated with quality of life and job satisfaction.<sup>12,13</sup> Our findings appear to suggest nuanced gains from salary and fringe benefits ranging from the money itself to what it can support to the affirmation of value in both home and work environments.

Our study expands upon a smaller qualitative study comparing employed persons with SCI ( $n = 6$ ) to unemployed ( $n = 6$ ), which found self-esteem, achievement orientation, optimism, and role modeling as psychological factors associated with employment.<sup>14</sup> Studies often note increased subjective well-being among employed compared to unemployed individuals<sup>15,16</sup>; our participants acknowledged it as an incentive to work and emphasized emotional health and psychological well-being. This study has profound implications for policies that present financial barriers, not simply to becoming employed but to retaining employment, working full-time, and maximizing earnings. In short, any policy presenting barriers either to maximizing employment or earnings also may have the unintended consequence of decreasing life expectancy. This is supported by previous research on mortality.<sup>17</sup>

It seems notable that while salary was mentioned as important to pay for personal care attendants and private transportation, it was not mentioned as being critical to cover health care

costs in any of the focus groups. This absence of an otherwise expected narrative may suggest that return to employment may not be possible after SCI unless a mechanism exists to cover other health care costs.

The theme emphasizing the importance of health insurance and other fringe benefits in motivating individuals with SCI to return to or maintain work complements existing research that notes how fear of losing health care benefits (primarily as associated with public assistance programs) limits some people from searching for or maintaining employment. Even with this group who had returned to work following SCI, there were different levels of willingness to trust in full-time employment to provide both sufficient income and needed benefits such that they gave up Medicaid and other public assistance supports.

## Limitations

This is a qualitative study. As such, the themes identified were dependent upon both the individuals who attended each group and the structure and facilitation of the groups. We attempted to engage participants who represented a range of backgrounds and place them in groups based on education or other characteristics that would be most likely to allow relevant themes to emerge. Identifying potential participants based on data they provided in other studies facilitated this process but may limit the generalization because most of these individuals had gone through rehabilitation at a regional SCI center.

Another potential limitation for many qualitative studies is the validity of the themes identified. We have taken steps to limit threats to validity that can come from haphazard processing, analysis, or interpretation of the narratives through engaging in standardized procedures. In particular, we used a transcription process and data analytic methods to limit these threats to validity and also added elements to the plan of evaluation to ensure 90% agreement in coding between the 2 coders.



## Conclusion and implications

Employment after SCI – whether returning to work or finding a first job—is an important decision that should not be minimized or taken lightly. Many people with SCI (whether newly injured or many years after injury) are in their prime working years. For these people, work may not only provide money to support a certain lifestyle (such as having a family, home, a car, etc), but may also give a sense of identity, social connections, and a reason to get up in the morning. These benefits are multifaceted and go beyond monetary compensation.

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